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DIVISION OF FAMILY HEALTH SERVICES

RESPONSE TO PROJECT SERVE

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PART I - INTRODUCTION

This paper represents the Massachusetts Department of Public Health's statement of policy and program direction to be pursued in coming years in response to the challenge of Project Serve to "continue the pioneering tradition of Title V agencies in staking out new ground and shaping the quality of services for children with special health care needs."

Project Serve,¹ a federally funded Special Project of Regional and National Significance (SPRANS) was developed to address issues of access, equity, and unmet needs raised on both the state and national level in discussions and studies concerning public sector responsibility for children with chronic/disabling conditions. Its report New Directions: Serving Children with Special Health Care Needs in Massachusetts was issued in November 1985 and contains fourteen recommendations aimed at defining, focusing and broadening the role of the Massachusetts Department of Public Health in serving children with special health care needs. The recommendations represent the culmination of three years of study involving extensive data collection and analysis of the needs of handicapped and chronically ill children in Massachusetts.

Project Serve findings indicate that there are approximately one hundred thousand children in Massachusetts, age birth to twenty-two, with a chronic illness or disabling condition which requires specialized health and related services. To fulfil the Commonwealth's commitment to this population and address the gaps that exist in meeting the special needs of these children and their families, attention is required beyond that accorded to the health care needs of able-bodied children and

¹ *The Massachusetts Department of Public Health, Division of Family Health Services, was one of three agencies which participated in this public/private collaboration together with the Harvard School of Public Health, Department of Maternal and Child Health, and the Children's Hospital Medical Center, Developmental Evaluation Clinic (University Affiliated Facility)*



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their families. In general, chronic illnesses/disabilities of childhood share the following characteristics:

- The diseases/disabilities are costly to treat; even in the presence of third-party insurance, out of pocket expenses are high.
- The burden of care, year in and year out, falls on the family, with resources for family support being sparse and non-reimbursable.
- Services are fragmented, and integration of care takes on enormous magnitude for families who are involved with a multiplicity of professionals, providers, and state and federal agencies. Integration of primary, secondary and tertiary care is virtually non-existent.
- There is tremendous variation in the quality and comprehensiveness of care families receive based on: availability of specialty care and support services within the child's community; training and knowledge of the professionals providing services; and access to care in relation to socio-economic status, health insurance coverage, language and cultural barriers.
- The current health insurance system discriminates against families with a disabled or chronically ill child resulting in limited job mobility, financial hardship and decreased access to services.

Project Serve recommended that the Department of Public Health's role in carrying out the Commonwealth's responsibilities to these children, should be to:

- Plan for, ensure access to, and monitor the quality of a comprehensive and coordinated range of medical and support services for children with a disability or chronic illness and their families.
- Serve as an advocate for children with a disability or chronic illness and their families and provide leadership in identifying their needs and ensuring that their rights are protected.

- ° Work in cooperation with other public and private agencies and with constituency groups to assure that the needs of these children are met within a comprehensive service delivery system.

The Department of Public Health concurring in principle with this broad definition of its role, initiated a process to review in depth each of the fourteen Project Serve recommendations. This process included wide dissemination of the "New Directions" report and establishment through its Division of Family Health Services, of five committees and a steering committee to address the individual recommendations.² Each committee was charged with reviewing its assigned Project Serve recommendations, assessing feasibility and implications, recommending acceptance, modification, future study or rejection, indicating priorities, identifying needed resources, and outlining, where possible, an implementation process. The three recommendations not addressed by these committees (numbers 1, 3, 5, relative to planning, training and technical assistance, and innovation) were set aside for later study. The five committees completed their work in the summer of 1986, and from August through December, the steering committee worked to analyze, synthesize and organize the committees' work.³

The policy and program shifts presented in the following paper are the results of this process. They represent a long term commitment by the Massachusetts Department of Public Health to shaping a system of care that is responsive to the special characteristics and needs of disabled and chronically ill children and their families in a changing environment of service delivery and reimbursement.

² *A listing of committee membership and the recommendations each committee focused on may be found in Appendix A.*

³ *Committee reports may be found in Appendix B. Those wishing more background on the recommendations and the findings which led to them are directed to the Project Serve report entitled New Directions.*

PART II - NEW DIRECTIONS

The Massachusetts Department of Public Health accepts the challenge to serve as the lead public agency for addressing the health-related needs of handicapped and chronically ill children and their families. The Department, through its maternal and child health agency, the Division of Family Health Services, has unique expertise with which to address the needs of these children and their families. This expertise and experience has been recognized by the legislative and executive branches by the increased appropriation of funds and by the designation of the Department as the lead agency for multiply handicapped children and for early intervention services to at-risk and disabled children birth to three. *In recognition of this broader role and consistent with national trends, the Services for Handicapped Children's section of the Division of Family Health Services will change its name to Services for Children with Special Health Care Needs.*

The Department envisions its lead role in serving this special population as encompassing needs assessment, planning and program development, standard setting and monitoring, health education and training, and constituency building to bring the needs of this population into the public and legislative arena. Defining a public role which complements and enhances the private health care system, supports families in their roles as care givers and advocates for their children, and utilizes public resources in a manner which is equitable and has the ability to reach an expanded portion of the target population will be a primary objective. A partnership with the private health care sector, other public agencies, and parents/consumers will be forged to ensure availability and access to a comprehensive continuum of care and a broad array of family support services.

The Department concurs with Project Serve that one of the major changes that must occur is a shift of limited resources away from the direct provision of clinical care within the Division's Services for Handicapped Children Clinic Program and the encouragement and support the delivery of comprehensive quality specialty services within the private sector.

The Services for Handicapped Children (SHC) Clinic Program serves only selected diagnoses, almost exclusively children with physically handicapping conditions, and reaches only five percent of the target population. In some areas SHC clinics duplicate existing resources. In Boston, an area in which the largest number of urban disadvantaged children reside, SHC does not operate clinics. Thus many children in the state are not touched by the SHC system even though they have complex health care needs and are in families with significantly lower incomes than those receiving SHC services. In addition SHC clinics are non-reimbursable by third party insurers. Such services are reimbursable when provided in the private sector. Thus, the Division's delivery of specialty services, while of high quality, fails to use public dollars efficiently.

The Department agrees that a more appropriate role for a state agency relative to the provision of specialty care, lies in the areas of standards development, technical assistance, monitoring and certification, provision of incentives for the development of innovative models of care, provision of a broad range of health education activities for health professionals, school personnel and families, and the purchase of services not traditionally reimbursed by third parties. Through such a shift in focus, the Department will develop the capacity to influence the availability and quality of specialty services for a significantly larger number of handicapped as well as chronically ill children.

The shift away from the delivery of direct care will enable the Department to concentrate a greater portion of its energy and resources on expanding support services for families, thereby enhancing the ability of families to nurture their handicapped and chronically ill children.

The Department recognizes that it is of critical importance to provide a continuum of supports for the family as primary care giver. The continuum should have as its primary goal that of maximizing the developmental potential of each child while maintaining the integrity of the family. Services within the continuum should be aimed at maintaining the child

within the home environment, but should also provide alternative out of home settings when these are more appropriate for meeting the needs of the child. Home health care, respite, camperships, specialized equipment, adaptive housing, information and referral services, case management, information on rights and entitlements, financial counseling, family counseling and parent and sibling support groups must be available, accessible and affordable for all families who need them.

The Department, with legislative support, has made expansion and innovation in this area a priority over the past several years. Expansion of home health services in FY'84 and FY'87, the addition of adaptive housing in FY'84, the acquisition of funds to develop and implement training and recruitment programs for home health aides, foster and adoptive care families, and the provision of home-like residential alternatives for severely and multiply disabled children represent recent initiatives. The Department intends to continue to build upon this existing base of services and strengthen its efforts to assure the provision of a continuum of care that is accessible and responsive to the individual child and family's needs within the context of their ethnic, racial and cultural background.

Early identification, access to information and referral services, case management and advocacy are essential to the effective delivery of services that address the child and family's needs. Although the Department has deferred consideration of Project Serve's recommendation for mandated reporting of severely involved children, it is committed to promoting activities which support early identification and referral and activities which enable families of severely involved children to negotiate the health care system. These activities include:

- ° Development of an expanded system of services for children birth to three.
- ° Advocacy for entitlement to coordinated interagency planning and service delivery for severely involved children requiring services from multiple human service and education agencies.

- ° Advocacy for a single entry point for such services.
- ° Empowerment of parents.
- ° Development of a state-of-the-art regionally based information and referral service.
- ° Maintenance and improvement of existing reporting systems such as the Division of Family Health Services's High Risk Infant Reporting System, and Early Intervention Management Information System and the Department of Public Welfare's Project Good Health.

As a first step in meeting this commitment, the Division of Family Health Services will expand its case management capacity statewide. The intent is to make these services more accessible and available, to extend expertise into new areas such as counseling families in health insurance coverage and financial planning and to devote additional resources to parent empowerment activities.

Underlying all of the Department's efforts to respond to the challenges of Project Serve is the belief that parent participation in the planning and design of programs both for their own child and at a systems level, is essential to the delivery of services that meet the child and family's needs. The Department through its Division of Family Health Services, intends to foster such participation in the following ways:

- ° Develop training programs for parents to assist them in becoming knowledgeable about available resources and services, in advocating for and assuming case management responsibility for their children, and in enhancing their skills in interagency case conferencing and development of individual plans.
- ° Explore means for supporting and promoting parent empowerment and parent to parent networks.
- ° Increase participation of parents in Division planning and program development.
- ° Require vendors to demonstrate mechanisms for parent involvement in individual care planning and programming.

At the heart of the Department's "New Directions" is the ability to impact on access to services for a broader population of disabled/chronically ill children and their families. Key to this will be strengthening the role of the four public health regional offices and establishing a fifth office with a full complement of services to cover metropolitan Boston. These offices are in a unique position to monitor the changing needs and the availability of resources for these children and their families. Their knowledge of the demographics and politics of the local communities, their contacts with school systems, consumers and advocacy groups, providers and health professionals, and their ability to enhance inter-agency collaboration and planning at the local level should be utilized to full advantage. The regional offices will serve as the entry point for information and referral services; be a primary source for technical assistance, consultation and health education; provide coordinators of services and case managers for severely involved children and families; and monitor the quality and availability of health and support services.

A major barrier to access for disabled/chronically ill children and their families is the absence of, or lack of adequate health insurance. While fundamental changes will only occur through legislative and regulatory action, the Department can play an important role by becoming a public voice in advocating for the promotion of reform in the health insurance industry. To this end, an Office of Finance and Resource Development needs to be established within the Division of Family Health Services' Policy Office to carry out the following responsibilities:

- ° Monitor and review proposed state policies and legislation affecting the financing of care for children and families.
- ° Maintain liaison with public and private agencies involved in health care financing to bring the needs of target populations to their attention.
- ° Conduct or fund special studies on financial barriers to health care for children.
- ° Develop resource and training materials and conduct training for staff, families, other public agencies, special interest groups, providers.
- ° Serve as the focal point for the development of proposed legislation affecting insurance coverage, rates and rules of access for the Division's target populations

The Division also intends to develop the capacity to counsel families on financial planning and health insurance coverage to enhance their ability to make prudent choices in providing financial and health protection for themselves and their children.

PART III - RESOURCE REQUIREMENTS

To fully implement the new directions, roles and functions described, the Department will need to reallocate current resources, seek additional funding, and work to increase resources available through other public and private agencies.

The shift away from the direct provision of care will allow a sizeable professional staff of nurses, physical and occupational therapists, and social workers within the four public health regional offices to perform many of the new roles and functions. An extensive knowledge of public health principles and practices and a community orientation will enable existing staff to transfer skills from direct service to new and expanded roles with a minimum of training. These professionals with their broad knowledge of pediatric disabilities and chronic illnesses are qualified to:

- ° Function as clinical care specialists within the regional offices or within the private sector who coordinate the planning and delivery of clinical and therapeutic services to children who must deal with a multiplicity of agencies or multiple specialists within a single institution.
- ° Provide consultation, technical assistance, training and education to health care facilities, school systems, consumer groups, community agencies, state and federal agencies.
- ° Provide case management services.
- ° Monitor and evaluate the availability, accessibility and quality of health care and family support services.

Regional support staff will have expanded opportunities by being trained to take on new roles such as intake worker, hot-line operator for information and referral services, and financial counselors.

A major portion of the approximately one million dollars budgeted annually for the purchase of medical services, medications and specialized

equipment for children enrolled in the Services for Handicapped Children's clinic system will gradually be used to expand family support services. The extent and timing of this shift in resources will in part depend upon the results of the Commission on Health Care Financing and Delivery Reform's study of the state's uninsured populations. Lack of health care insurance, inadequate coverage, lack of reimbursement for specialized equipment, and the current demands upon the hospital free care pool may make it necessary for the Division of Family Health Services to continue to pay for medically related services for some children for the foreseeable future. The amendment of the state Medicaid plan to include severely disabled children at risk for institutionalization, without deeming parental income, will also if approved, allow for more flexible use of Department resources which are presently providing medical and support services for this group of children.

National recognition of emphasis on family related issues may provide promise for utilizing federal funds to achieve some of the outlined changes and expansion. Congress has authorized a seventy-five million dollar increase in the federal appropriation for the FY'87 Maternal and Child Health Block Grant and has earmarked one third of any additional state appropriation for use for services to children; including primary care, case management and community based service networks for disabled children. If this money is appropriated, Massachusetts would gain close to one million four hundred thousand dollars, of which over four hundred thousand would have to be devoted to children's services. Increased Block Grant funds would ensure maintenance of current budget levels and allow for limited expansion for case management and other family support services. Additionally, federal funds available as a result of P.L. 99-457, which amended the Education of the Handicapped Act to extend entitlement to developmental services to children birth to three, will support planning activities and expansion of services for the birth to three age group.

Resources, however, can only be stretched and redirected so far. New funding will be necessary to implement fully an extended system of family support services. State of the art computer software, hardware,

telephone hot lines in each regional office, and additional programmers and data analysts will be needed to develop an increased information capacity. Personnel with skills in health economics, epidemiology, health planning and standards development will be required. Establishment and staffing of a public health regional office covering Metropolitan Boston will be essential. Finally, the ability to provide leadership and incentives to support innovative practices, new service models and new treatment approaches will require an infusion of new money.

PART IV - PLANNING FOR CHANGE

A change in direction of the magnitude outlined will involve extensive planning and full implementation will take several years to complete.

Initially, planning will focus on implementing the shift away from the direct provision of clinical services. From a management standpoint, this is pivotal for accomplishing the majority of proposed changes, and from a strategic standpoint is the most complex. This planning effort will encompass a region by region inventory and evaluation of alternative sources of care, and an individualized discharge planning and follow-up of patients transferred to the private sector. Coordinated planning will be needed to establish partnerships with the private sector in the development of specialty services in areas where such services are not available, in the development of specialty care standards, and in the maximizing of available funding from other public and private third party payors.

There are approximately five thousand children served in sixty Services for Handicapped Children clinics statewide who will need to be transitioned into the private sector. Discharge of these children and closing of individual clinics will be contingent upon the availability and accessibility of comparable services within the private sector. The Department is committed during this process, to maintaining continuity of care for individual children and families and to ensuring that these children continue to receive quality comprehensive services, preferably within or close to their home communities. To accomplish this, a transition planning committee will be established within the Division of Family Health Services' central office and within each of the regional public health offices. The central office committee will coordinate and support the transition process in each region and will be responsible for:

- ° Developing statewide transition policies and protocols.
- ° Developing instruments for classifying patients, following-up discharged patients, and assessing provider service capacity.

- ° Providing technical assistance to regional staff in identifying appropriate service providers.
- ° Conducting initial negotiations with providers relative to establishment of specialty care services, standards of care, fiscal arrangements, monitoring, etc.

The regional transition committees will be responsible for:

- ° Overseeing implementation of the discharge planning and follow-up process.
- ° Conducting regional surveys of available resources and identifying service gaps.
- ° Prioritizing clinics for transition and closure.
- ° Overseeing transition of children and families to alternative care providers.

Concomitantly, the Department is committed to promoting and developing a statewide specialty care delivery system to provide quality care to handicapped and chronically ill children in Massachusetts. The system will encompass tertiary care centers, community hospitals, community health centers, health maintenance organizations, and private practitioners. Establishment of a certification and monitoring system tied to specialty care standards will be essential to promoting this quality care system. A core set of standards which address basic criteria such as service components, staffing, coordination of services, including linkages to primary care providers, provider quality, and patient rights, will be developed to be used in certifying tertiary care/specialty care delivery systems. Diagnosis specific standards which address individual diagnoses or groups of related diagnoses will also be developed to individualize and expand upon basic criteria included in the core standards. The Department will create a statewide task force to develop these standards. Participants will include pediatricians, specialists, other health care professionals, providers, consumers, third party payors and state agencies.

Standards, once developed, will be used as the basis for certification, which will be voluntary; Public Health funding will be made available only to certified settings; and third party payors will be

encouraged to link payment to Department of Public Health certification status. Initiating negotiations with Medicaid relative to linking payment of their service dollars to certification status will be imperative for assuring that quality services reach the neediest of the state's handicapped and chronically ill children and families. Precedence for this type of arrangement already exists within the Department's early intervention programs.

The shift away from the direct provision of care will require role changes for a large number of regional professionals. The Department is committed to accomplishing change in a manner which protects the rights of employees and recognizes long-term commitment to the Services for Handicapped Children program, while enabling and facilitating management's ability to implement a new service delivery system. Careful consideration will be given to addressing Civil Service and Union issues, developing training programs and resources, researching alternative work options and providing job counseling and support services for personnel throughout the entire transition phase. Here again, a committee will be established within the Division of Family Health Services' central office and within each of the regional offices to plan for role transition. The central office committee will be responsible for coordinating and supporting the role transition process within each region by defining goals, objectives, tasks and strategies, developing job descriptions, organizing training programs, and working with the Civil Service Administration and the various Unions. The regional committees will be responsible for overseeing the matching of individual staff skills with new roles, determining individual training and support needs, and overseeing the transitioning of personnel into new roles. New functions will be introduced gradually as direct care loads decrease.

Major planning initiatives will also be taking place to implement P.L. 99-457. The Department of Public Health has been designated as the lead agency for implementing the provisions of this new federal legislation. Division of Family Health Services staff are already preparing the groundwork for a four year planning cycle that will result in an entitlement to early intervention services for children birth to three.

The Division of Family Health Services will also evaluate its management structure and its ability to provide the framework within which to carry out the planned initiatives and directions. Such an evaluation will focus on the Division's organizational structure, and its administrative, statistical, and planning systems. Project Serve recommendations #1 and #3 regarding planning, training and technical assistance will also be more carefully studied at this time.

Throughout the process, the Department will work closely with the Executive Office of Human Services and the Legislature. Currently a number of state task forces and commissions are examining various aspects of the state service system for children. Policy and organizational decisions resulting from the Foster Care Commission, the Task Force on Children's Mental Health Services, the restructuring of the Department of Mental Health and establishment of the Department of Mental Retardation, may have implications for the Department of Public Health's planning process. The Department is committed to work closely with these groups and agencies and to be a key participant in decisions affecting handicapped and chronically ill children.

The Department will also work closely with key individuals and groups within the private sector to ensure a smooth transition and development of an effective system of care. Existing mechanisms for communication and advice will be fully utilized. These include the Family Health Services Advisory Council, the Early Intervention Advisory Council, and the regional public hearing process instituted to receive testimony on the Maternal and Child Health Block Grant. The Division's newsletter, the Bulletin, will cover the progress of the transition. The Department will also seek to develop additional mechanisms for input at the regional and community levels including working with organizations such as the Federation for Children with Special Needs, local advocacy groups, and local Councils for Children.

In summary, this paper signals the acceptance by the Massachusetts Department of Public Health of the new directions recommended by Project Serve, and the Department's readiness to translate them into "NEW DIRECTIONS". This paper also marks the beginning of a planning process which will require active participation and support of the Executive and Legislative branches of state government, health and human service professionals, providers, advocates, consumers and parents. With their support and guidance, the Department of Public Health is confident that the future holds improved family centered and community based services for children with special health care needs.

